

SCOTLAND'S CARERS MANIFESTO 2011 - 2015



These 14 carers from Scotland's health boards represent:

*** More than 140 years of caring ***

*** More than 36,400 hours of care provided in one year ***

*** Just £39,239.20 paid annually in Carers Allowance – that's 92p per hour ***

"I am glad that I am caring for my husband but I've have to give up so much - my career, time to myself, holidays... and money is tight.. I have had to constantly fight for the little help we get. It's not fair. What carers do is so important."

No more talk... action now!

Carers are essential to our communities and to our economy

Carers are a national resource. It is vital that there is a national consensus on issues that impact on their lives. Every political party in Scotland has a responsibility to design a fair system that supports and rewards carers, bringing together resources from a range of services and policy portfolios to enable carers to have a quality life of their own.

- 1 in 8 of the population are carers.
- There are almost 660,000 carers in Scotland; over 115,000 care for over 50 hours a week.
- There are over 100,000 young carers aged from 3-18 years in Scotland; 21% spend between 30-39 hours per week caring.
- There are more carers than the total health and social care workforce.
- Replacing the care provided by unpaid carers would cost three quarters of the total NHS budget in Scotland – £7.68 billion each year.
- By 2025, the economy will need to draw another 200,000 people into the workforce. We cannot afford to lose carers from the labour market as we move from recession to growth.

Scotland's carers must have a right to:

- Support to assist them in their caring role.
- A regular break.
- A life outside of caring.

Scotland's young carers must have a right to:

- Be children and young people first.
- Have the same opportunities and life chances as their peers.
- Reach their full potential.

As a minimum, each political party must commit to:

- Implementing 'Caring Together' Scotland's Carers Strategy and "Getting it Right for Young Carers".
- Realigning resources to enhance support for carers across Scotland and improve their lives.
- Implementing a carers rights charter and extend further rights to carers.
- Ensuring that unpaid carers do not suffer disadvantage because they cannot access appropriate services or experience an increased burden of care as a result of the "shifting the balance of care" agenda.

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Every carer deserves the right to: Support to help them in their caring role

Caring for someone is emotionally and physically demanding. Crisis situations can develop without appropriate support, requiring more complex and costly interventions.

It is essential that carers have access to information and advice, training, emotional support and advocacy. Local and national carers' organisations in Scotland provide that support and are a lifeline for unpaid carers in Scotland. Stable and secure funding will ensure they have the capacity to work with every carer who needs accessible and dedicated services.

Carers should also be supported to maintain their own health and wellbeing and to have opportunities to access social and leisure activities to reduce isolation and improve wellbeing.

- 19% of carers say if they had received more support as a carer, it would have prevented the person they care for being (re) admitted to hospital.
- Only three areas in Scotland provide access to advocacy service to help them get the services they and their families need.
- Carers who have taken part in expert training are more able to manage their caring situation and feel that caring had less of a negative impact on their health.
- 80% of carers have been forced to give up leisure activities because of caring. Three quarters have lost touch with members of their family and friends.
- Half of carers who provide intensive care have been treated for anxiety, depression or mental ill health.

What carers say:

"At the outset it was a real horror story. I did not know what was happening. There was no one to tell me what was happening."

"What I did feel was that I could have coped better at home if I'd known the things I knew as a result of the course."

As a minimum, each political party must commit to

- Securing and sustaining funding for carers' organisations. £11.1 million would ensure there is continued support to enable carers to continue caring. That's just £14.66 per carer per annum.
- Continuing to prioritise and invest in strategies which inform carers of their rights and offer training and skills development opportunities to carers, enabling them to have more confidence and manage their caring role.
- Ensuring carers are prioritised within primary care and psychological services, to access help and early treatment for anxiety, depression or mental ill health.
- Prioritising carers within national and local health and wellbeing strategies and providing regular health checks to carers as means of preventing ill health and the breakdown of caring.

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Every carer deserves the right to: A regular quality break

Regular breaks from caring are essential to carers if they are to continue their caring role. Research shows us the benefits and cost savings of short breaks – but many people still can't access the services and supports they need which enable them to have an appropriate break.

This means that carers and their families struggle on until they can no longer cope, often resulting in hospitalisation, emotional and physical exhaustion. This increases pressure on local services as crisis situations develop.

Every carer and their family has a right to a break from caring. They should have a choice of services that can meet different or changing needs. No one in need should be prevented from having a break for financial reasons.

- Carers still identify the right to regular, high quality short breaks services as their top priority.
- 39% of carers have not had a break from their caring responsibilities lasting longer than 2 days.
- Increasingly breaks are only offered as “emergency relief” meaning that carers and families cannot access respite and short breaks which could prevent crisis situations.

What carers say:

“My mother in law is going to be older. She is going to need more care and if there are no services in place then we are going to end up being ground into the ground by having to be there 24 hours caring”

“Short breaks mean everything to our family. They give us the ability to recharge and carry on.”

As a minimum, each political party must commit to:

- Ensuring there are enough resources available to improve the quality, choice and availability of short break services, recognising cost savings generated as a result.
- Developing a nationally coordinated Short Break Transformation Fund to help local authorities, Health Boards and their planning partners move from crisis-led to preventative short break services.
- Putting in place the necessary plans and resources so that national priorities for short break improvements are translated into local action and that progress can be measured.

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Every carer deserves the right to: A life outside caring

Recent research demonstrates that over three quarters of carers do not have a life of their own outside of caring. They cannot take up learning or leisure opportunities or the day to day activities that we all take for granted.

For many, the right support would enable them to stay in employment and continue caring. Access to flexible working opportunities can prevent a loss of skills and reduce business costs for recruitment and training. Where carers cannot combine work and caring, there should be imaginative lifelong learning opportunities which can enable them to have a life outside caring and to move more quickly into employment once caring ends.

Approximately £1.8 billion is spent on skills and learning in Scotland. Despite the substantial and growing number of carers in Scotland, the disadvantage faced by many young carers and the potential contribution of carers to the labour market, economic and skills strategies do not recognise them as a priority group. Finding and maintaining employment is a route out of poverty – and this applies equally to carers.

Carers often experience significant levels of poverty as a consequence of caring including debt, difficulty in meeting household expenses and fuel poverty. The largest proportion of carers live in the most deprived areas in Scotland. However, the Scottish Government and local authorities do not recognise them as a priority group. Benefits remained reserved to Westminster but much more could be done to integrate carers' specific needs into policies to tackle poverty and disadvantage in Scotland.

- One in five carers have had to give up their career or turn down a job because of their caring responsibilities.
- 72% of carers are financially worse off because of their caring role – giving up work to care contributes to carer poverty. On average carers have lost £11,000 per annum in income as a result of this.
- 75% of carers live in fuel poverty. More carers experience fuel poverty than any other group in society.

What carers say:

"Because of these huge increases in fuel costs I cannot afford to feed my family properly. We are using 24/7 gas and electricity consumption which is higher than those who go out to work."

"After 16 years of caring I feel out of touch with the world of work and unconfident going back to my previous job. I feel humiliated by being on benefits."

"[Social services] have taken the pressure off, I mean they help her with her breakfast, they help her with her lunch, and then they help in the evening... otherwise we'd be running backwards and forwards. Also, having a job where you can be flexible gives you an opportunity to get away from the situation you are in, and it gives you time to be yourself at work without those outside pressures. It keeps you fresher than if you are there 100% of the time caring, as that can get on top of you."

As a minimum, each political party must commit to:

- Extending initiatives to prevent fuel poverty, such as enhanced measures within the Scottish Energy Assistance Package to carers.
- Including carers, as a target group who face particular disadvantage within national and local economic and skills development strategies and employment support initiatives.
- Working with public and private sector employers, including small business, to promote flexible working and carer friendly working practices.

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Every carer deserves the right to: Be a child and young person first

Over 100,000 young carers provide emotional, physical and practical support to a family member who could not manage without this. This can lead to problems because they are taking on caring responsibilities which are inappropriate for their age; they miss out on school and learning, and face challenges in the transition from school to adulthood. They can lose out on many of the normal childhood experiences enjoyed by their peers.

Young carers' futures can be affected by their caring roles. It is imperative that organisations such as Skills Development Scotland, schools and universities play a key role, working in partnership with schools, health and social care professionals, in helping young carers to achieve their full personal and academic potential and make a successful transition into adulthood and the world of work.

Young carers receive specialist support from young carers' services. For every £1 invested in these, over £6 is saved for statutory services as a result of better outcomes in education, less young people going into care and the support they receive which reduces inappropriate caring.

- 70% of young carers say that caring makes their life more difficult.
- Young carers say they need more understanding and support from staff in education, health and social services.
- In a recent mapping exercise, none of the local authorities could provide estimates of the numbers of young carers who received support from mainstream services.
- Young carers have little access to advocacy services to help them get the services and support they and their families need.

What young carers say:

"My doctor doesn't listen when I try to talk to him about my mum, says it just cause of her illness when I know it's not just cause of that."

*"In my school they did understand my situation because I talked to my guidance teacher. After that they helped me and my brothers to get transport to go and see my mum in the hospital.
My registration teacher was the best."*

As a minimum, each political party must commit to

- Implementing the action points in the national young carers strategy
- Developing effective support for young carers provided by an appropriately skilled and competent workforce across universal services
- Securing sustainable funding to strengthen the capacity of dedicated young carers services

Published by Scotland's national carer organisations:
Carers Scotland, Crossroads Caring Scotland, the Coalition of Carers in Scotland,
The Princess Royal Trust for Carers, the Scottish Young Carers Services Alliance and Shared Care Scotland.

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